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Natural Language Processing for Patient Information

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Despite the proven cost effectiveness of patient education, there is still a well-documented information gap between doctors and patients. Many practitioners are looking toward tailored, computer-based patient health information and advice to fill this gap. In this paper, I first describe an intelligent interactive patient information system, the Migraine system, which I helped develop before the widespread adoption of the world wide web (WWW). I then describe how the WWW and recent advances in natural language technology may be marshalled to build the next generation of intelligent personalized patient information delivery systems on the web.

Introduction

Many medical practitioners perceive a need for patient education. Patients' attitudes to their ailments and their therapies influence clinical success. Patient education increases patient satisfaction with their treatment, and this in turn leads to better compliance. For example, in the treatment of diabetes, education aimed at increasing patients' understanding of their condition was shown to increase patients' desire and ability to take more responsibility for their own care [20]. This ultimately leads to better outcomes, such as reduced hospital admissions and length of stay, less use of emergency facilities [38], and better quality of life for patients [33]. A meta-analysis of patient education studies shows that patient education saves significantly more money than the original investment, often by a factor of three or more, by avoiding future health services utilization [2, 34].

However, despite the recognized need for patient education, there is a well-documented "information gap" between doctors and patients, e.g., [16, 18, 39, 47, 49]. Wallen et al. found that physicians spent less than 1% of total talking time providing explanations to patients [48]. Moreover, there is substantial evidence that doctors and patients use different language [26, 50] and therefore, even when physicians are able to take the time to give patients detailed explanations concerning diagnosis or treatment, patients may not understand the terms or concepts used. Furthermore, there is a striking asymmetry in information exchange between physicians and patients: in medical discourse, physicians ask the questions and patients provide the answers [18, 49]. When patients do make direct information requests of their doctors, the answers they receive tend to be brief. In short, interaction between physicians and patients tends to be structured in such a way that information flows

from patient to doctor but not *vice versa*. This asymmetry reduces the quality and quantity of information received by patients and may contribute to reduced compliance [19, 25].

In an attempt to provide patients with information about their therapy, many clinics now give patients pre-printed handouts about their disease and drugs. There are several problems with relying on handouts to do the job of patient education, especially for conditions such as migraine. First, handouts about migraine tend to be lengthy because there are many different types of migraine and many different combinations of symptoms that patients may experience. Several studies show that impersonal, decontextualized information has significantly less impact on patients than selective presentation of relevant, patient-specific information, e.g., [1, 10, 27, 45]. Second, research on the effectiveness of such handouts indicates that they are of limited use unless clinical personnel review them with patients to ensure comprehension and answer questions [21]. Finally, with printed handouts, patients cannot ask follow-up questions or further explore topics they are interested in. Static, printed matter does not encourage exploration.

Given the current realities of the health care systems in countries like the USA and UK, increasing the amount of time that physicians spend communicating with patients is not a viable option. Moreover, clinical personnel are not trained in patient education. For this reason, there is a clear role for intelligent computer-based information delivery to patients. Indeed, patients already make extensive use of on-line sources. An estimated 29% of Americans use the internet for medical care, often before consulting a physician (Newell, personal communication). Thus, it is in the interest of health care providers to make high-quality information available via the Internet and to provide tools for supporting patient information seeking, gathering, analysis and exploration.

In this paper, I'll first describe an intelligent interactive patient information system, the Migraine system, which I helped develop before the widespread adoption of the world wide web (WWW). I then describe how the WWW and recent advances in natural language technology may be marshalled to build the next generation of intelligent personalized patient information delivery systems on the web.

An Intelligent Interactive System for Patient Information Delivery

Our goal in the Migraine project was to facilitate the exchange of information between patients and physicians and to provide patients with information they do not seek from their physicians or do not fully comprehend when it is provided. We chose migraine therapy for several reasons. Migraine affects approximately 20% of the population [23], and causes considerable discomfort and loss of work time, reducing the quality of life of migraine sufferers. The cost to employers of employees' migraines is \$5256 to \$6864 per year for each male and \$3168 to \$3600 per year for each female [44]. Diagnosis of headache depends primarily on a thorough history of symptoms. Effective treatment of migraine is complicated by the fact that about half of the patients do not get sufficient relief from the regimen initially prescribed. Finding the proper medicine and dosage may require a long series of visits to the clinic. With migraine patients, effective information exchange between physician and patient is critical: patients must be motivated to return for further visits even when their treatment to date appears to have been unsuccessful.

In the Migraine project, we sought to overcome the limitations of preprinted handouts, and to make the reading of informative materials more like human-human communication. Our main objectives were to present information that is relevant to the individual patient and that takes their concerns into account, and to design an interface that would allow patients to get as much information as they wanted and the system could provide. Indeed, one of the major challenges was to design an interactive situation that made it easy and natural for patients to pose queries and to get the information they desire. Thus, the Migraine system tailors the information it provides to the individual patient's medical history, diagnosis, lifestyle and therapy. Then, once the initial tailored information sheet has been displayed on the screen, the system allows the user to request further information by pointing to system-generated text that they do not understand or would like more information about. In response to their pointing, the system dynamically generates a menu of patient- and context-sensitive questions that may be asked about the selected text.

Figure 1 shows a high level view of the interactive system we designed and implemented. The migraine system [6] consists of three main components. The interactive **history-taking module** collects information about the patient's medical history, allergies, past medication, lifestyle, and so on, in order to build the patient model and to produce a printed summary of the patient's history, which is presented to the physician before the consultation with the patient and is added to the patient's chart after the visit. After the patient has given a history, he is seen by the physician, who then provides the system with information about the diagnosis and the prescribed therapy.¹ After seeing the doctor, the patient in-

¹ Note that before the patient uses the explanation module, the physician or other clinical personnel must provide the system with information about the diagnosis and the prescribed therapy. To expedite this process, we built an interactive interface that prompts the physician for the needed information, and provides warnings such as interactions between drugs being prescribed for migraine and other drugs

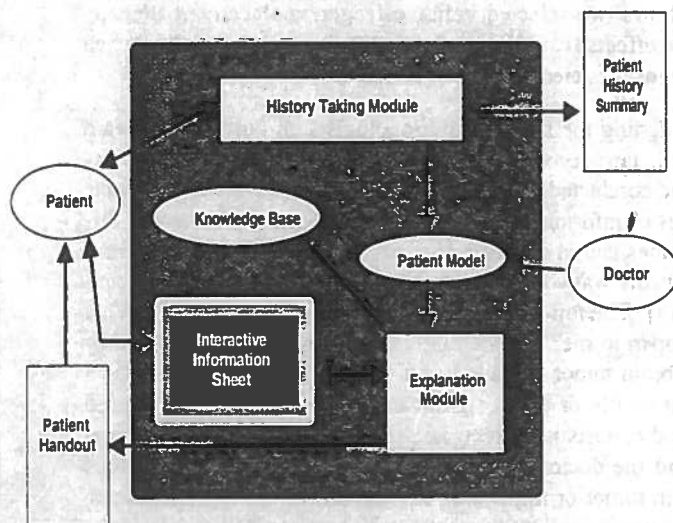


Figure 1: Overview of Migraine System

teracts with the intelligent **explanation module**, which produces an initial interactive information sheet containing explanations in everyday language that is tailored to the individual patient using the information stored in the patient model and a dialogue history containing information about prior explanations the patient has received. The **interaction manager** presents the interactive information sheet on the screen and manages the subsequent interaction with the patient, passing requests for further information to the explanation component to produce additional patient- and context-sensitive responses. When the patient has finished with the explanation component, the system prints out a transcript of the conversation that the user has had with the system.

Figure 2 shows a snapshot of the interactive information sheet produced by the Migraine system for an individual patient who has been diagnosed as having migraine. The figure shows the cursor, which appears as an arrow, being moved over the first sentence in the third paragraph. As the cursor is moved over parts of the sentence, a box appears over the smallest constituent about which follow-up questions may be asked. For example, if the cursor is currently over a noun phrase, e.g., "migraine", a box would appear around the noun phrase. When the cursor is over the verb, a box appears around the clause containing that verb. In the figure, the cursor is currently over the connective "while", which relates the two clauses in this complex sentence, and thus the system draws a box around the entire sentence. By moving the cursor over parts of the sentence and observing which text objects appear in boxes, the user can explore options for asking further questions about statements made by the system (clauses and sentences) or the terms used in them (noun phrases). When the user identifies a boxed text object that she would like to ask further questions about, she selects it by clicking the mouse in the box. The selected item then becomes highlighted (indicated in reverse video), and a menu of possible follow up questions about the selected item appears. Fig-

the patient is taking.

ure 2 shows two selected items, **estrogen replacement therapy** and **side effects from ibuprofen** and the menus that appear when these items are elected.

In designing the system, anthropologists on our research team observed, tape-recorded, and transcribed doctor-patient interactions and conducted interviews with patients, in order to determine the types of information needs that migraine sufferers have at different times and in different contexts. An important finding from the fieldwork was what Forsythe termed hierarchy of patients' concerns [17]. The top-level question for migraine patients is, "What will happen to me?" Since migraine patients often fear that they have a brain tumor or have had a stroke, this is understood as a question of life or death significance. They want to be assured that the diagnosis is correct, i.e., that it accounts for their symptoms and the doctor is not overlooking something more serious like brain tumor or impending stroke. Lower down in the hierarchy are questions about the triggers, treatments, and causes of the condition. Each step in the hierarchy is associated with a particular set of information needs. Knowledge of this hierarchy was useful in designing the structure and content of the interactive information sheet. For example, the text presented to patients deals with global concerns (e.g., alleviating patients' fears that they are suffering from a life-threatening condition) before going on to instruct patients about how to follow their therapy regimen.

In addition, to ensure that we covered information that doctors wanted to convey to their patients, we interviewed physicians, and also asked the physicians on our research team to write sample information sheets for several actual patients. Finally, to help ensure that we were composing texts in language that patients could understand, we examined sample handouts being given out in local hospitals, clinics and pharmacies, as well as a number of texts extracted from books and pamphlets explaining migraine concepts to a lay audience. Based on these analyses, lists of questions pertaining to various topics were developed. We used these analyses in two ways: (1) to devise the library of explanation strategies that our text planner uses to construct explanations, and (2) to identify the information needs that these explanations were intended to fulfill and the potential follow-up questions that they might evoke. analysis, we developed the heuristics used by the system to generate follow-up questions dynamically.

Explanation module: A more detailed view

Most patient information systems generate their messages by piecing together sentences that have been written *a priori*, filling in slots with information pertaining to the current patient. Sentences are selected for inclusion based on aspects of the patient's medical history, diagnosis and prescribed therapy, and slots are filled with patient-specific values (e.g., name of patient and doctor, test result value, prescribed drug). In contrast, our system generates the text dynamically by reasoning about, and recording, not only what the system says to the patient, but also why (i.e., the communicative goal(s) of the explanation) and how (i.e., via what explanation strategies the system conveys that information). Using intelligent text generation in such a system has two major advantages: (1)

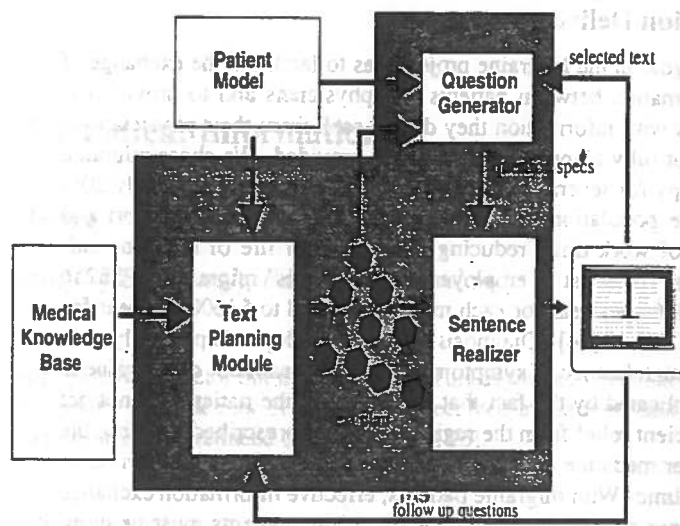


Figure 3: Explanation Component

It allows the system to produce explanations that are tailored not only to aspects of the patient history, but also to *the history of the questions and answers that have been exchanged thus far*. (2) It provides the underlying knowledge structures needed to support an interface that allows patients to ask follow-up questions about system-generated text in a natural and flexible way. Results from the fieldwork indicated that patient-users often do not fully understand or accept explanations as they are first given [6], and thus the system was designed to be interactive. It allows patients to ask additional questions until they are satisfied. As noted above, patients initiate queries simply by pointing to portions of the system's explanations about which they would like further information. The length of the dialogue (and therefore of the printout that the patient receives) is thus controlled by the patient. Since the patient controls the duration and content of the dialogue, any information beyond that presented in the initial information sheet is directly relevant to the patient's concerns. This differs from preprinted materials, which inevitably present some information that is not relevant to individual readers. Moreover, because the interface suggests topics that the patient can explore, it encourages patients to take a more active role in learning about their disease and therapy. Printed material cannot actively engage the reader in the same way.

Figure 3 shows a more detailed view of the explanation module and how it interacts with other components in the system. The explanation system consists of a text planner, a sentence generator, and a question generator. The text planner selects and organizes the content to be included in a text, using a library of plan operators encoding discourse strategies that enable it to design texts to achieve different communicative goals. Communicative goals represent the effect(s) that the explanation is intended to have on the patient's knowledge or goals, e.g., "describe diagnosis," "describe side effects of Inderal". At the beginning of the interaction, the interaction manager posts the goal to generate the initial information sheet for this particular patient. A schematic view of a portion of the plan generated by the text planner for the interactive

Figure 2: A snapshot of the system with some of the dynamically generated menus.

information sheet is shown in Figure 4.

To produce an explanation that achieves the communicative goal(s), the planner searches its library of explanation operators, looking for candidates that can achieve the goal(s). As noted above, these operators were derived by analyzing naturally occurring explanations gathered during the fieldwork on doctor-patient interactions, handouts given in local clinics, books that explain migraine concepts to a lay audience, and explanations constructed by our physician experts.

Explanation operators encode standard ways that communicative goals are achieved by rhetorical means. Each operator encodes the following information:

- **effect(s):** communicative goal(s) the operator is intended to achieve
- **preconditions:** conditions that must hold for an act to successfully execute. For example, the patient may need to be at a certain stage in the hierarchy of concerns a particular discourse strategy to be effective.
- **constraints:** specifications of the knowledge resources needed by the discourse strategy. These criteria can refer to the system's medical knowledge base, the patient model, or the dialogue history.
- **subplan:** optionally, a sequence of steps that implement the discourse strategy

- **rhetorical structure:** information about the discourse relations (e.g., cause, evidence, exemplification) between steps in subplans.

Figure 5 shows two (simplified) plan operators used in the system. The first operator applies only if the patient is female, premenopausal and does not have a history of estrogen drugs. The second operator satisfies the same goal as the first, but is only applicable to male patients. The explanations generated for the two cases differ substantially, with the first patient being provided information about the effect of menopause on migraines in addition to the information on aging. The system has approximately 280 operators dealing with different situations. The majority of these operators refer to the patient model in their applicability constraints.

In general, there may be many strategies capable of achieving a given goal, so the planner employs a set of selection heuristics to determine which of the candidate strategies is most appropriate in the current situation. These selection heuristics take into account (i) the specificity of the operators (in general, more specific operators are chosen over more general ones); (ii) information about the patient's history and preferences (as recorded in the patient model); and (iii) the conversation that has occurred so far (as recorded in the dialogue history).

Once a strategy is selected, it may in turn post subgoals for the

Figure 5: Sample Plan Operators.

planner to refine. For example, the two steps of the first operator shown in Figure 5 post two subgoals. Planning continues by refining subgoals in this fashion until all communicative goals have been refined to speech acts (e.g., INFORM and RECOMMEND). The plan is then recorded in the dialogue history, and passed to the realization component, which uses templates to produce actual English sentences.

The Interaction Manager

The advent of systems that automatically generate text poses new opportunities as well as new problems. Interviews with patients indicated that they often had questions about their diagnosis and treatment that they didn't ask their physicians, or that they didn't completely understand or accept the answers to. Studies of human-machine interactions in other domains also show that information-seekers often follow up requests for information with further questions [24, 32, 35]. This illustrates the fact that initial explanations are seldom sufficient to satisfy users in real situations, and also underscores the need for computer-based information-giving systems to offer facilities that allow users to ask follow up questions.

This capability is especially crucial in applications such as patient education where misunderstandings could result in serious consequences.

When texts are not prepared *a priori*, techniques combining hypertext and canned menus cannot be applied to enable users to ask for further information. Indeed, building an interface that allows users flexibility in asking follow up questions from automatically generated explanations presents a difficult challenge. If the system allows users to pose their questions in unrestricted natural language, it must be able to handle questions or statements that refer to previously given explanations, e.g., "*Could you please explain that last part in more detail?*" Free text questions that refer to prior discourse are beyond the capabilities of current natural language understanding systems because they mix references to domain entities and discourse entities. But, even if technology for handling free text input were available, we would still need a way to constrain users to ask only those questions that the system can answer.

One alternative, which is to provide a restricted query language, is also problematic. Users find such languages difficult to learn and frustrating to use. If the query language is a subset of English, interference from other synonymous, natural ways of phrasing questions makes it difficult for users to recall the restricted set of allowable inputs [3]. Thus, restricted languages are especially unsuitable for infrequent users. Moreover, restricted query languages require that users be able to pose well-formulated follow up questions. Users who are confused may not know exactly what question they wish to ask. Restricted query languages typically provide "catch-all" menu options, such as "More" or "Huh?". However, we have found that in many cases, users can be more precise about what they wish to ask than these "catch-all" options allow, even if they cannot formulate a question in a specific query

language.

To alleviate these problems, we devised an interface in which system-generated texts are structured objects that can be directly manipulated. With our interface, users point to the portions of system generated text that they do not understand or would like more information about, and the system provides a menu of questions that may be asked about the selected text. Question menus are generated on the fly taking into account the patient model, underlying knowledge bases, and the prior discourse context. This approach provides a simple and intuitive interface for allowing users to pose follow up questions about system-generated utterances, and at the same time circumscribes the set of questions users may ask without requiring them to learn a restricted language.

For such an interface to be feasible, the system must be able to understand what the user is pointing at, that is, the system must have a model of its own explanations including the goals of the explanation and how the generated text achieves those goals. But this is precisely what the completed text plans produced by the explanation planning module provide. A text plan is an explicit representation of the planning or "design" process that produces an explanation, it records not only the individual clauses that make up the text, but also the reasons behind each clause (i.e., the communicative goal(s) that led to their inclusion), and the semantic and rhetorical relations between items (e.g., cause, contrast).

When the planning process is complete, the realization component traverses the text plan, collecting templates for clauses and the semantic and rhetorical relations that connect them. These form a sequence of objects that will then be presented on the screen by the interaction manager. It is important to note that the sequence of objects constructed during this process is not simply a sequence of text strings. Rather, each object in the set has an associated set of display properties, e.g., font, color, inverse video, and whether or not the displayed object should be mouse sensitive when it is displayed. To implement the direct manipulation interface, linkages from the actual English text on the screen, through the objects that the realizer creates, and eventually back to data structures in the text plan are maintained in a dialogue history.

As described above, to pose questions about text the system has generated, the user moves the mouse over the generated text, and those portions that can be asked about become highlighted. The templates that are built by the realizer distinguish between noun phrases (objects), whole clauses, and complex sentences connected by discourse markers (e.g., "because", "for example"). Because the system has a record of the plan that produced the text, as well as a patient model, the system can reason about the context in which the selected text occurs, and provide a menu of follow-up questions that is sensitive to both the discourse context and the individual patient.

For example, consider the portions of the information sheet shown in Figure 6. The term migraine occurs in several places in the portion of text shown here. Clicking on different occurrences of the term migraine causes the system to present the user with different

Today you saw Dr. Rivers, who diagnosed you as suffering from **migraine**. The most common symptom of migraine is a moderate to severe headache. Migraine patients...

Migraine is also strongly hereditary. You report that some of your family members have had severe headaches that are similar to yours....

Migraine (Diagnosis)	Migraine (Hereditary)
What is migraine? Is migraine dangerous? What causes migraine? Can migraine be cured? Physiology, experience and medical implications of migraine...	Is migraine always hereditary? Will my children suffer from migraine? What is migraine?

Figure 6: Menus generated in different contexts

questions, since the term occurs in different contexts. If the user selected the term migraine in the first paragraph (indicated in bold in the figure) where it occurs in a sentence that introduces the disease, the generated menu (shown on the left) would contain very general questions. In contrast, if the user selected the term migraine in the first sentence of the second paragraph (indicated in italics in the figure) which describes the hereditary nature of the disease, the menu would include questions about this aspect of the disease (shown on the right in the figure.)

Using this interface, users may also select whole clauses, which correspond to speech acts in the underlying representation. A speech act consists of two parts: its type, which indicates the manner in which the information is to be communicated, and the information itself. The information to be communicated is represented as a predicate followed by some number of arguments. When the user selects a clause, the system generates questions based on:

- the type of speech act that produced the clause
- the propositional content of the clause (represented as a predicate followed by some number of arguments), and
- the rhetorical relation between this proposition and any others in the text plan

In the knowledge base, we have specified the types of question appropriate for each predicate type. For instance, predicates which are causal relations give rise to questions such as "How can X cause Y?". For example, the "trigger" relation, which is a type of causal relation, results in: "How can red wine trigger migraine?" Similarly, attributive relations result in: "What are the <attributes> of X?", and so on. The system also generates "What is a ...?" questions for each of the arguments to the predicate in the speech act.

Figure 7 shows an example of the menu generated when the user selects a clause, which corresponds to an INFORM speech act in the text plan. The propositional content of the speech act is a type of causal relation between Motrin and stomach pain. Using knowledge about how to form questions from causal propositions, the

1):

Headache take 800 mg of Motrin, up to 3 times per day. Motrin helps to relieve the pain in most patients. Some patients experience side effects from Motrin. You may experience stomach pain or discomfort. If you can take food without vomiting, this may help you to tolerate the Motrin better...

Side effects of Motrin

Why does Motrin cause stomach pain or discomfort?
What are other common side effects of Motrin?
What can I do to reduce common side effects of Motrin?
What is stomach pain or discomfort?

Figure 7: Menu generated from INFORM act

system can form the first question in the menu. In addition, because this speech act occurs as part of a plan intended to make the hearer know about the common side effects of Motrin, the system generates the second and third questions. Finally, the system generates the fourth question from the arguments to the predicate. Note that the system does not generate the question "What is Motrin?" because this speech act occurs in the context of a text plan whose top-level goal is to answer this question.

It is important to keep in mind that although the interface described here bears a resemblance to a hypertext-style interface, the system is *not* a hypertext system in the traditional sense, i.e., it is not organized as a collection of canned pieces of text interconnected by typed links. Explanations are dynamically generated by the system as part of the initial information sheet or in responses to a patient's question. Because the text is generated dynamically, we cannot in advance identify the particular text objects that should be mouse-sensitive nor the links to other objects. Portions of text that should be mouse-sensitive can only be determined during the generation process, when the abstract rules for determining which types of objects should be mouse-sensitive are applied to the particular instances of text that are being generated. Finally, follow-up questions, which correspond to the links in traditional hypertext systems, are not pre-coded and fixed in advance, but are generated dynamically using heuristics that are sensitive to domain knowledge, the user model, and the discourse context.

There are two main advantages to this approach. First, what follow-up questions are meaningful is highly context-dependent. Because one of the main problems with hypertext systems is that users get lost in the network and may even forget what it was they were originally seeking [8], it is especially important to present the user with a small set of pertinent follow-up questions as opposed to a larger set of questions, many of which may seem off the topic or even irrelevant [24]. In our system, dialogue context (provided by the text plan) and the user model are exploited by strategies that prune the list of possible questions down to those that appear most relevant. Second, and perhaps most importantly, the abstractions we have devised for automatically generating follow-up questions relieve system builders of the intractable task of handcrafting all of the links and subsequent texts. For example, in the migraine

Table 1: User responses to survey questions

Questions	Answer Category	
	Yes	No
Did you like using the program?	16 (100%)	0 (0%)
Did all of the information presented make sense?	13 (81%)	3 (19%)
Did you feel comfortable about using a computer to get this kind of information?	16 (100%)	0 (0%)
Was the computer itself easy to use?	14 (88%)	2 (12%)
Did the system tell you anything you did not already know?	15 (94%)	1 (6%)
Do you think this information will help you manage your headaches better?	9 (56%)	7 (44%)
Did you learn anything that you would not have asked your doctor?	12 (75%)	4 (25%)

education system, there are approximately 75 factors that are used to tailor the explanations generated. These factors include information about patient symptoms, family history, drugs prescribed, their side effects, and so on. Writing separate explanations for different permutations and combinations of these 75 factors, as well as defining the links for each of the follow up questions would be an insurmountable task. And these variations do not even take into account the context created by any previous dialogue with the user! Clearly, providing a technology that can automate the generation of the texts and the linkages between them will greatly reduce the time taken to develop such systems.

Preliminary Evaluation of Usability and Utility

The usability and utility of the migraine system was evaluated in three preliminary studies. Two of these studies are relevant to the evaluation of the interactive information sheet. In the first study, 3 patients used the system in the context of an actual visit with a neurologist. In the second study, 13 persons with headache and one or more symptoms of migraine interacted with the history taking and the interactive information sheet without seeing the neurologist. The patient history and the medications being used by the patient were input to the system, along with instructions to the patients that the system would behave as though they had been diagnosed by the neurologist as suffering from migraine. In both of these studies, the patients were observed using the system, and were also interviewed afterwards regarding their session with the system. The system also recorded all mouse clicks and user commands, and this time-stamped history log was used in conjunction with the personal interviews in determining both problematic as well as interesting aspects of the generated handout. While we recognize that this is an evaluation of patients perceptions, and not a study of outcomes, we nevertheless believe that the results strongly suggest that such an interface is both intuitive and useful in applications such as the one described here. Table 1 shows some of the survey questions asked and the number of users answering in each category.

We also looked at the amount time users spent on the system and the number of follow up questions asked. The average amount of time users spent working with the system was 46 minutes, with interactions ranging from 14 to 160 minutes. This implies that users

pent significant amounts of time reading material other than what was presented in the initial information sheet. In addition, on average 11 different text objects were selected by users for further querying (the minimum being 1 and the maximum being 29). Furthermore, users often selected the same utterance several times, asking different questions each time. The average total number of questions asked by users in a session was 16, ranging from a low of 3 to a high of 45. These usage statistics underscore the need for providing a dialogue facility and designing interactivity into the system.

To gain a better understanding of the quality of the question generation scheme used in the system, we compared the set of questions capable of being generated by the system to a set of questions collected by one of the ethnographers from an analysis of 80 doctor-patient consultation sessions. Based on these analyses and interviews, the ethnographer compiled a set of 166 questions that arose in these sessions. The system can currently generate a total of 180 questions based on the current knowledge base and discourse plan operators. Of these, 142 are from the set determined by the ethnographic analysis. Thus, the system's coverage of this set is 86%. Of the remaining 24 questions in this set that the system does not generate, many deal with social and pragmatic issues. For instance, patients were concerned about how to explain their condition to their employers. Thus, there were a relatively small number of questions that users would have liked to have asked the system, but were unable to do so.

The main criticism was that the program did not have information specifically about the drugs they were taking, a problem we anticipated because the knowledge base is incomplete. Indeed, acquiring and regularly updating drug information automatically from existing databases is an area for future work, and would alleviate this problem.

In general, users found the system easy to use and stated that the interface helped them find relevant information easily. 88% of the users reported that the organization of the initial explanation and the questions generated were "intuitive." In addition, twelve of the users also stated that the questions in the menus had helped them learn things that they *would not have thought of asking their doctor*.² Thus, three-fourths of our users came across questions generated by the system that resulted in their learning about some aspect of migraine that it would not have occurred to them to ask about. This indicates that such an interface is helpful to users, *not just in presenting queries to the system, but also in exploring additional, related information that the system may possess about the topic*. It is clear that a more extensive and controlled evaluation is necessary before the actual benefits of such an interface can be determined.

²This is different from the questions which, according to the ethnographic analysis, *would not* have been asked by the patients, either because they felt uncomfortable asking those questions, or were intimidated by the doctor. Questions in this category, dealing mainly with the possibility of strokes and cancer—which almost never figured directly in the transcripts of doctor-patient interactions—were almost universally selected by users in our study.

Migraine in 2000

The migraine system was designed and developed when the WWW was in its infancy and largely restricted to academic researchers. After the encouraging formative evaluation of the prototype migraine system, we hoped to do a larger scale evaluation in neurologists clinics with patients going through the entire process as intended in our design. At this point, many of the problems in fielding the migraine system become logistical ones: where to put computers in already crowded clinics, who would support them, how to handle patients' questions about how to operate the computer, and so on. For an evaluation, we planned to have project personnel in the clinic, but this is clearly not a realistic solution for widespread use of patient information delivery systems.

Fortunately, however, the fast-growing use of the WWW by the general public at home, and in libraries, cyber cafes and community centers, makes on-line health information delivery not only possible, but a growing trend that many patients are already using and an increasing number of health care providers are exploiting.

Re-engineering the migraine system to provide a web-based service would be a fairly straightforward task. In fact, much of the technology for gathering information about users and exploiting it to customize interaction over the web already exists and is being used for many applications, including health promotion and advice. For example, Quitnet [41] provides on-line resources to help smokers overcome nicotine addiction. It includes questionnaires that are used to assess the user's level in the Stages of Change Model (a model of behavior change [40]) and to produce advice appropriate to the user's stage. However, tailoring of messages is done simply by selecting canned sentences, and no mechanism for allowing users to ask for further information from the program is provided.³

There is no doubt the existing system could be re-engineered to work efficiently as a web-based service, but several important developments have occurred over the past 5-7 years that I believe would reduce development time significantly, and could provide patients with an interface that facilitates exploration of the many potentially relevant documents on the WWW. Here I consider how we could harness recent developments in building medical ontologies as well as state-of-the art natural language processing capabilities to provide the kind of intelligent, tailored information delivery that the migraine system was intended to provide.

Migraine is a knowledge-based system, and thus the technology depends on a rich underlying representation of the domain content described in the generated text, as well as a model of the textual structure. Acquiring the domain knowledge for migraine required a substantial amount of project effort. If we were building that system today, we would expect to exploit the many knowledge bases and ontologies that are being built to support a wide array medical informatics applications, e.g., OpenGalen [37, 42], and databases containing information about preparations, side effects, and con-

³Although there are links to other web-based sources of information related to quitting smoking, several bulletin boards and chat rooms, and an "ask and expert" forum.

traindications of drugs [36, 5]. As part of our research on the migraine project, we attempted to automatically construct portions of the knowledge base from the UMLS semantic network [28], but we were able to devise only a semi-automatic process [9]. However, the GALEN Common Reference Model is represented in the GRAIL concept modelling language, a description-logic based formalism like the one used in building the original Migraine knowledge base, and thus the process of building a knowledge base suitable for a system such as Migraine from GALEN should be a much simpler task.

Another component of Migraine that required substantial effort was the explanation component, which was responsible for producing the initial information sheet and responses to subsequent questions. Much of the effort went into devising the explanation operators encoding discourse strategies for producing both the initial information sheet and the responses to the many questions users can ask during the open-ended, patient-directed interaction. This required acquiring knowledge about what to include in the initial information sheet and responses to follow-up questions for individual patients based on their medical history, stage in the hierarchy of concerns, and the history of the messages presented by the system. There are now several other systems that produce tailored material using techniques similar to Migraine, e.g., [12, 43], and all have found devising the explanation operators (or schemas) to require significant effort.

Assuming that something equivalent to the initial information sheet could be produced for all patients, either using knowledge based methods and full text planning or by mail-merge techniques [7, 11, 38, 45], how could we harness the vast information source available on the WWW for use in patient information exploration? Work in information retrieval and automated summarization of existing text could be very useful for this purpose. For example, techniques for automatically extracting "named entities" (basically noun phrases) from existing texts [31] and generating indexes from unrestricted text for information retrieval [13] could be used to identify the noun phrases in a given document. Thus, we can expect that such indexes will (or could) be available for many, if not all, documents on the WWW. In addition, parsers and part-of-speech taggers can robustly identify the constituents of sentences [4, 30, 15]. Building on these existing technologies would allow an interface in which all noun phrases in a document become mouse-sensitive, and the hyperlinks to other documents are determined on demand by using the noun-phrase (and perhaps synonyms identified using Wordnet [14]) as an index to find related documents. Techniques developed for automatic summarization of documents [22, 46], especially those developed for generating summaries from multiple documents [29], could be used to generate concise answers from relevant existing documents. Using these techniques would relieve system builders of the burden of representing the domain knowledge and discourse strategies for responding to user's questions, but would not allow the generation of responses that take the dialogue history into account. Studies to determine if and how much patient compliance and satisfaction is affected by the capabilities offered by the different techniques is

crucial in determining how future patient delivery systems should be built.

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